



2016 Title V Needs Assessment

Appendices

Appendix A: Criteria for Prioritization of Need Statements

General Stakeholders

Number of Individuals affected:	The number of individuals impacted by the problem. 1= few individuals are affected 5= many individuals are affected
Economic Impact:	The extent to which addressing the problem could reduce the financial burden on the community/state. 1= little economic impact on community/state 5= large economic impact on community/state
Degree of Demographic Disparity:	The degree of disparity among different populations as it relates to the problem. 1= low disparity among different populations 5= high disparity among different populations
Severity of Issue:	The extent to which this problem affects the health and well-being of a population. 1= there is little impact on the health of the population 5= there is large impact on the health of the population
Family Impact:	The extent to which this problem has a great impact on families (i.e. quality of life, functionality). Examples include child cannot attend school or parent cannot work due to problem. 1= there is little impact on the family 5= there is a major impact on the family
Systems Change:	The extent to which addressing this problem maximizes and leverages opportunities for change. An example is an opportunity to implement a policy that applies to multiple provider types. 1= little opportunity to change the system involved 5= major opportunity to change the system involved

Additional Leadership Team Criteria

Motivation to change	<p>The extent to which there is a desire to address the issue (i.e. political will, department priority).</p> <p>1= there is little motivation to change</p> <p>5= there is a major motivation to change</p>
Issue can be tracked and measured	<p>The extent to which IDPH/CHSC has the ability to measure change over time (i.e. existing data source, available personnel).</p> <p>1= the issue cannot be tracked and measured with current resources</p> <p>5= the issue can be tracked and measured with current resources</p>
Effective intervention is available	<p>An effective intervention is available to address the issue (i.e. evidence-based curriculum, best-practices recommended by AAP).</p> <p>1= there is not a known effective intervention</p> <p>5= there is a known effective intervention</p>
Organizational Capacity	<p>There are adequate resources to address the issue (i.e. funding, personnel, partnerships).</p> <p>1= there are not enough resources available</p> <p>5= there are enough resources available</p>

Appendix B: Prioritization Survey Results

General Stakeholder Criteria:

	All Respondents	BFH/OH/ CHSC	BFH/OH/ CHSC + Agency Staff	Parents/ Clients	Intersted Stakeholders (One vote per group)	BFH	OHC	CHSC	Executive Directors
2: Access to Specialists for MCH	1	5	2	1	4	8	6	7	1
10: Transportation Resources	2	1	1	21	6	2	3	8	6
24: Transition to Adulthood Planning for CYHSCN	3	2	3	2	5	13	15	1	16
6: Adolescent Health Systems Coordination	4	9	6	5	1	5	16	10	3
12: Developmental Screenings	5	10	5	7	7	4	5	11	2
15: Maternal Mental Health System	6	12	4	16	9	1	11	13	10
8: Access to Child Care	7	8	7	10	8	3	7	12	4
19: Care Coordination for CYSHCN	8	4	9	3	15	15	9	3	12
20: Data Coordination for CYSHCN	9	7	11	15	3	17	12	4	13
22: Integration of Services for CYHSCN	10	3	8	11	13	16	14	2	15
1: Insurance Literacy for MCH	11	14	12	6	14	10	2	14	8
23: CYHSCN Value-Based Financing	12	11	10	8	12	22	19	6	9
3: Dental Delivery Strategies for MCH	13	16	13	4	11	14	1	16	5
21: Family Involvement in CYSHCN Decisions	14	13	15	12	10	19	21	9	11
11: Medical Home for Children & CYSHCN	15	6	14	17	17	11	4	5	17
7: Bullying Prevention System	16	15	17	9	2	18	23	15	7
17: Reproductive Health System	17	18	16	20	16	9	18	19	14
14: Chronic Disease Prevention for Women	18	21	19	19	18	12	10	21	18
13: Medical Home - Pregnant & PP Women	19	17	18	22	19	6	8	18	21
16: Prenatal Care System	20	20	20	14	20	7	13	20	19
4: Breastfeeding Support	21	19	21	13	22	20	20	17	22
9: Injury/Environmental Risk Prevention	22	22	22	18	21	21	22	23	20
5: Safe Sleep Resources	23	23	23	23	24	23	24	22	24
18: Maternal Occupational Risks	24	24	24	24	23	24	17	24	23

Legend: Ranked 1-5 Ranked 6-13 Ranked 14-24

Detailed Criteria results and Leadership Criteria:

	Main Criteria						Leadership Criteria				Averages		
	Number Affected	Economics	Disparity	Severity	Family Impact	Systems	Motivation to Change	Trackable	Intervention Available	Org Capacity	Main Criteria Avg	Leadership Crit	All
2: Access to Specialists for MCH	4.0	4.0	4.0	4.2	4.0	3.9	4.0	3.5	2.3	2.2	4.0	3.0	3.6
10: Transportation Resources	3.8	3.8	4.2	4.0	4.2	4.0	3.3	3.7	3.1	2.5	4.0	3.2	3.7
24: Transition to Adulthood Planning for CYHSCN	3.6	4.2	3.7	4.0	4.2	4.1	3.9	3.4	3.9	2.7	4.0	3.5	3.8
6: Adolescent Health Systems Coordination	4.0	4.0	3.9	4.0	3.9	3.9	3.9	2.2	2.7	3.0	3.9	2.9	3.5
12: Developmental Screenings	3.7	4.1	3.8	4.0	3.9	3.9	4.1	3.5	4.2	3.5	3.9	3.8	3.9
15: Maternal Mental Health System	3.6	3.8	3.7	4.1	4.3	3.8	4.2	3.2	3.5	2.9	3.9	3.5	3.7
8: Access to Child Care	3.8	3.8	3.9	3.8	4.2	3.8	3.0	2.9	2.6	2.1	3.9	2.7	3.4
19: Care Coordination for CYSHCN	3.4	3.9	3.7	3.9	4.2	3.9	4.3	3.7	4.0	3.6	3.8	3.9	3.9
20: Data Coordination for CYSHCN	4.1	4.1	3.2	3.9	3.4	4.1	4.4	3.0	2.9	2.5	3.8	3.2	3.6
22: Integration of Services for CYHSCN	3.5	3.9	3.7	3.8	4.0	3.9	4.4	3.5	3.5	3.5	3.8	3.7	3.8
1: Insurance Literacy for MCH	3.5	3.9	3.8	4.0	3.8	3.7	3.6	2.6	2.6	3.3	3.8	3.0	3.5
23: CYHSCN Value-Based Financing	3.8	4.2	3.5	3.7	3.7	3.8	3.4	2.5	2.9	2.4	3.8	2.8	3.4
3: Dental Delivery Strategies for MCH	3.8	3.7	3.9	3.8	3.5	3.7	3.6	3.4	3.3	2.8	3.7	3.2	3.5
21: Family Involvement in CYSHCN Decisions	3.8	3.4	3.6	3.6	3.8	3.7	3.4	2.9	4.1	3.3	3.7	3.4	3.6
11: Medical Home for Children & CYSHCN	3.3	3.8	3.8	3.7	3.7	3.5	4.3	4.0	3.9	3.4	3.6	3.9	3.8
7: Bullying Prevention System	3.8	3.0	3.2	3.9	3.9	3.6	3.9	2.1	2.4	2.5	3.6	2.7	3.2
17: Reproductive Health System	3.3	3.7	3.6	3.4	3.6	3.4	3.0	2.9	3.1	2.8	3.5	2.9	3.3
14: Chronic Disease Prevention for Women	3.3	3.4	3.5	3.4	3.4	3.4	3.0	2.3	2.3	2.2	3.4	2.5	3.0
13: Medical Home - Pregnant & PP Women	3.0	3.5	3.5	3.4	3.3	3.4	3.7	3.5	3.0	2.6	3.3	3.2	3.3
16: Prenatal Care System	3.0	3.5	3.6	3.4	3.3	3.3	3.3	3.1	3.0	3.0	3.3	3.1	3.2
4: Breastfeeding Support	3.3	3.3	3.4	3.4	2.8	3.2	3.3	3.6	3.0	2.7	3.2	3.1	3.2
9: Injury/Environmental Risk Prevention	2.7	3.3	3.1	3.0	3.1	3.0	2.7	4.1	2.9	1.9	3.0	2.9	3.0
5: Safe Sleep Resources	2.7	2.5	3.3	3.0	2.7	2.8	3.5	2.8	3.9	3.3	2.8	3.4	3.0
18: Maternal Occupational Risks	2.4	2.8	2.9	2.7	2.8	2.7	2.1	1.7	3.0	1.6	2.7	2.1	2.5

Appendix C: IDPH Agency Protocol for Iowa's Title V Maternal and Child Health Program

Agency Information Sheet

Overview: The Iowa Department of Public Health is conducting focus groups to assess the quality of our care coordination activities in Maternal and Child Health programs. Specifically, we want to know, "How are we doing? What can we do to improve?"

We are not assessing individual agency quality or practices, but rather, hope to create a state-wide snapshot of Care Coordination in our programs.

Impact: These data will be used to understand best practices for Care Coordination in Iowa, as well as how MCH Care Coordination can be improved. IDPH is creating a best practices guide for MCH care coordination, as well as creating an on-line Care Coordination training. These focus groups will be used to inform both. Additionally, these focus groups will serve as a pilot for future client-based qualitative data collection, including the Title V needs assessment.

Planning: We have selected one Child Health and one Maternal Health agency in each region to sample clients for focus groups. One focus group will be held with clients of each selected agency. **Your agency has been selected to participate in a CHILD OR MATERNAL Health focus group.**

IDPH will work with you to plan the focus group, including finding an appropriate date, time and location to hold the focus group. Ideally, we would like to find a non-agency location, such as a public library, to hold focus groups. Food will be provided, so outside food must be allowed. We would also like to provide a \$10 gift to participants. This could be a gift card (to somewhere that does not sell alcohol or tobacco), coupon for specific items, or other material, such as books, toys or other resources. Your contract will be amended to fund these incentives. We also will need to provide child care during the focus groups. This may be accomplished by holding the focus group during a library's story hour, or other event, or by providing agency staff for childcare.

Recruitment: Clients have been randomly selected from CARES and WHIS. 30 clients have been randomly pulled for each agency. Attached is your list of clients to contact. Please call clients in the order they are listed until 10 clients have been recruited for participation. Please have them verbally confirm that they would like to participate and are available at the date and time of the focus group. If fewer than 7 clients are able to be recruited from the list, please recruit clients from your **Maternal/Child** health client list. You may select clients from this list as you see fit. We ask that you send an informational letter (attached) to each person who agrees to participate. Please add confirmed participants' name, phone number, and any special requirements to the attendance sheet (attached). A few days prior to the focus group, please place a reminder call to each participant.

Information for client: When recruiting clients, please inform the client of the following items:

- That the purpose of the focus group is to assess how we are doing on our MCH services, and what we can do to improve
- Date and time of focus group
- That childcare, and if needed, transportation will be provided (The agency is responsible for arranging and funding.)
- That neither participation, nor their responses to questions, will affect the services they receive now or in the future

- That although agency staff may know who attends the focus group, agency staff will NOT be present at the focus group and will not know what was said by whom
- That a thank-you gift will be provided
- If the client does not speak English, that they may participate in the project through a one-on-one translated interview. (Translation will be provided by non-agency staff)
- If they have any questions about the focus groups, they may contact Betsy Richey at 515-725- 2085.

Questions? Please contact Betsy Richey, BFH Data Integration Coordinator at 515-725-2085 or betsy.richey@idph.iowa.gov.

Focus Group Attendance Sheet:

Client Name	Phone Number	Focus Group or Individual Interview	Translator Needed? (specify language)	Transportation Needed?	Childcare needed?	Other Notes

Client Letter: Please place this letter on agency letterhead before sending.

<date>

Dear <client name>,

We are working with the Iowa Department of Public Health to find out how well we are able to meet the needs of you and your family. As discussed on the phone, you are invited to join in a group discussion about the services **you (your child)** received from this agency.

The discussion will be held **Date** at **location**. Childcare and transportation will be provided if needed. You will receive a small thank-you gift for participating.

Being part of the discussion is entirely voluntary, and information you provide is confidential. We will not know what you said, and only a state-wide anonymous report will be provided to us.

Someone from **the agency** will contact you a few days before the focus group as a reminder, and to answer any questions you may have.

Thank you,

this agency

Appendix D: IDPH Discussion Guides for Family Focus Groups Conducted by Iowa's Title V Maternal and Child Health Program

Focus Group Script

Welcome and Introduction

Thank you for participating in this focus group. The purpose of our discussion today is to get your input on how public health services for women, babies, and children can be improved in Iowa.

My name is _____; I will be leading today's conversation. This is _____, s/he will be taking notes, and maybe asking a few questions. We work at the Iowa Department of Public Health. We work with programs that try to help mothers and children get medical and dental care and are interested in whether we can improve your access to medical and dental care in Iowa - for you and your children.

We want to hear your honest opinion. There are no right or wrong answers. We just want hear your experiences and opinions. This focus group is totally **voluntary**. Your participation will not affect the services you receive from *(name of agency)* in the future. The information you provide will be used to make improvements to the way we help moms and their kids get health care in Iowa, so services in general may improve. This discussion is also totally **confidential**. Staff at *(name of agency)* will not know what you said today. They will receive a report of the state-wide results of these focus groups. Your name will not be attached to what you say at all. Each of you has a number sitting in front of you. We will use this number in the notes we take, instead of your name. We are also tape recording what you say. The recording will only be used to make sure our notes match up with what was said. The recording will be deleted as soon as we complete our notes. Only *(note taker name(s))* and I will hear this recording.

Do you have any questions?

Before starting, I want to go over a couple of things. We have scheduled 1.5 hours for our discussion, but we may finish up sooner. There are not any scheduled breaks, so please step out for a break as you need. The bathrooms are located [.....]. Also, please feel free to help yourself to the food. So as to not interrupt the discussion, could you please turn your cell phone to silent right now? As a thank you for your time, you will receive a \$10 gift certificate for Hy-Vee at the end.

Before we get started, I want to go over a few ground rules.

1. As we just said, there are no right or wrong answers. We want to hear a wide range of opinions, so please speak up if you agree or disagree.
2. We want everyone's participation. I may call on someone if we haven't heard from you in a while.
3. What is said in this room stays in this room. We want you to feel comfortable sharing, so please do not talk about this discussion outside of this room.
4. You may hear opinions today that are different from your own on many topics. Please be respectful of the opinions of others in the group.

Do you have any questions at this time?

Today, we are discussing the services you received from *(name of agency)* to support *(Maternal: you while you were pregnant; Child: your child in accessing healthcare services)*. Most of the services you receive are called 'care coordination'. You may have also received dental services, or a health screening.

Care coordination is the when someone at <agency> helps you to get medical or dental care; by reminding you about appointments, helping you make appointments, helping you get transportation to the appointments – those types of things. Most care coordination is provided over the phone, but may also be done in person, or by text message or email.

Do you have any questions before we get started?

Focus Group Questions

The following are a list of ideas for questions for both the maternal and child health focus groups. Focus groups should have 6-8 main questions, and optional probe questions for each main one.

- Introductory question:
 - *Child Health:* How many children do you have, and what are they into right now?
 - *Maternal Health:* What do you like about your pregnancy?
- What was the reason that you used <name of agency's> services?
 - What services did you receive?
 - *Child Health only:* Does your child have special healthcare needs? If so, what?
- Were the people you talked to at <agency name> easy to talk to?
 - Do you feel like s/he understood your needs?
 - Was any information confusing or unclear to you?
- Do you remember when I just explained what care coordination is? Did you receive care coordination from <agency name>?
 - What is an example of a time that care coordination helped you?
 - What services did they help you to receive?
 - How did the agency help you to link with services that you needed? Was this helpful?
- Was there a time that care coordination didn't meet your needs?
 - What do you think would have been more helpful?
 - Can you think of ways that care coordination can be improved?
 - Did you receive the services you expected?
 - What could have been done better to help you?
 - What frustrations did you have?
 - Was it overwhelming and/or confusing?
 - Did you understand why you were being asked the questions you were asked?
- What additional services, outside of care coordination, do you need?
- What health services (medical and/or dental) are most important to you?
 - For yourself?
 - For your kids?
- Do you feel that you can access those services that are most important to you?
 - If yes, is it through the help of <agency name>?
 - If not, can you explain why not?
- What are the problems that you have seen or experienced affecting the health of mothers/children/families in your community? (generate group list)
 - What is your community doing to address these problems?
 - What more could be done?

- Do you think/expect the agency you receive services from can address these issues?
- Do you know people who would benefit from services who aren't receiving them?
 - What is their situation?

- Do you know why are they not getting services from <agency name>?
- How can public health better reach out to them?
- What question do you wish I had asked you?
 - Other comments

Wrap up:

Thank you for your time and feedback today. We really appreciate your participation. You are helping to make health services for moms and kids in Iowa better across the state, and what you say here will not impact the services you receive. If you have any questions, or have additional information to provide, please don't hesitate to contact Betsy Richey. She is coordinating these focus groups. Her contact information is on the sheet we provided to you at the beginning.

As a thank-you for participating today, here is a \$10 gift card to Hy-Vee.

Informed Consent Handout

Iowa Department of Public Health Maternal and Child Health Focus Groups

Purpose:

- To understand how well Maternal and Child Public Health services are meeting clients' needs
- To identify any barriers or gaps in services clients experience
- To identify other resources that would help to improve Iowa's women and children's' health and wellbeing

Your participation in this discussion will not affect the services you receive. However, the information you provide will be used to improve the maternal and child health system in Iowa, so services in general may improve.

This focus group is totally **voluntary**. You can choose to participate in this focus group, but do not have to.

This discussion is totally **confidential**. Staff at this agency will not know what you said today. They will receive a state-wide report that does not contain any participant names or identifying information.

If you have any questions or additional information to add after this focus group, please contact Betsy Richey, IDPH Bureau of Family Health Data Integration Coordinator at 515-725-2085 or betsy.richey@idph.iowa.gov.

THANK YOU!!

Appendix E: Key Informant Interview Telephone Protocol for Five Year Needs Assessment for Iowa's Title V Program for Children and Youth With Special Health Care Needs

Iowa's Child Health Specialty Clinics (CHSC), in its role as administrator for Iowa's Title V program for children and youth with special health care needs (CYSHCN), is conducting its five-year needs assessment and developing an action plan based on identified needs and input from stakeholders like yourself. We will be talking to approximately 20 key leaders in the state who work with children and youth with special health care needs and their families. The objectives for these interviews are the following:

- Obtain (in your own words), a summary description of the services/activities your organization provides for and with CYSHCN and their families and how your organization currently works or collaborates with the State Title V Program for CYSHCN;
- Collect informed opinions of key stakeholders on the areas of strengths and weakness in the system of care for CYSHCN in Iowa; and
- Identify opportunities for action to improve this system of care, potentially in collaboration with your organization, and better serve the needs of CYSHCN in your state.

Interview Questions

1. How would you describe your organization's role in the system of care serving or working with children and youth with behavioral health care needs and their families?
2. How do you currently work or collaborate with the Title V program for CYSHCN to identify and serve children and youth with behavioral health care needs and their families in Iowa?
3. What do you think are the strengths of the overall system of care serving CYSHCN and their families in Iowa, particularly as they relate to the following nine areas:
 - a) *behavioral health care*
 - b) *access to a medical home*
 - c) *care coordination*
 - d) *oral health care*
 - e) *home and community based services*
 - f) *family/professional partnerships*
 - g) *availability of culturally and linguistically appropriate care*
 - h) *electronic data systems and other health information technology*
 - i) *financing and insurance coverage*

4. In each of these areas what do you think are the greatest weaknesses in the system (creating gaps or unmet needs for CYHSCN and their families)?

5. What do you see as the **areas of opportunity** that Iowa's Title V program for CYSHCN should focus on over the next five years to improve the system of care for CYSCHN and their families in this state?

Follow-up questions:

5a. What would be the unique role of Iowa's Title V program for CYSHCN in each of these areas?

5b. How can the state Title V program for CYSHCN collaborate or partner with your organization to make these system improvements?

Thank you. The State's Title V program for CYSHCN very much appreciates the time you are providing to think through these questions and provide input for future action planning to improve the system of care for CYSCHN and their families in Iowa.

**Appendix F: Organizations Represented in Key Informant Interviews for Iowa's Title V Program for
Children and Youth with Special Health Care Needs**

Iowa Chapter of the American Academy of Pediatrics
Ask Resource Center/Family to Family Health Information Center
Bureau of Learner Strategies and Supports, Iowa Department of Education
Blank Children's Hospital
Division of Mental Health and Disability Services, Iowa Department of Human Services
Early ACCESS, Iowa Department of Education
Iowa Center on Health Disparities, University of Northern Iowa
Iowa Medicaid Enterprise, Iowa Department of Human Services
Iowa Primary Care Association
Magellan Behavioral Care of Iowa (manages Iowa's Medicaid Behavioral Care, including Pediatric Integrated Health Homes
Meridian Health Plan (manages Iowa's Temporary Assistance for Needy Families Medicaid Managed Care Plan)
NAMI (National Alliance on Mental Illness) Iowa
Office of Minority Health, Iowa Department of Public Health
Office on the Status of African Americans, Iowa Department of Human Rights
University of Iowa Children's Hospital
University of Iowa, College of Dentistry and Dental Clinics, Department of Pediatric Dentistry
University of Iowa Health Care, Department of Family Medicine
University of Iowa Health Care Alliance
Wellmark Blue Cross Blue Shield of Iowa

**Appendix G: Focus Group Procedures for Iowa's Title V Program for Children and Youth
with Special Health Care Needs**

As you know, CHSC is collaborating with the Iowa Department of Public Health to complete a five year needs assessment, which we will include as part of our Federal Fiscal Year 2016 MCH Block Grant Application. As part of this process to determine the needs of families we serve, a consultant hired by CHSC is conducting focus groups around the state with families we currently serve.

We would like to conduct a focus group in your community and request your help in recruiting families to participate. The focus group in your community will occur:

DATE, TIME, LOCATION

Instructions: Using your patient list of families served by your Regional Center **in the past 12 months**, call the family of every **fifth child until 10 families agree to participate**. Use the attached script to call and ask if they are available and interested in participating. If you call and nobody answers, simply call the next family rather than waiting for them to call you back. If you reach the end of the list and do not have 10 participants, start again at the top of the list and call the family of every **fourth** child. The focus group in your community will be conducted in English, so please only recruit families that use English as their primary language. We will conduct a focus group in Spanish in Northwest Iowa.

Each focus group will be held in a central location and will last about an hour and a half. Staff from your Regional Center do not need to attend. To compensate participants for their time, child care, and travel costs, each participant will receive \$60. Food will be provided. We hope that this payment can cover the cost of childcare during the focus group, but it is okay to bring the child to the focus group if the family cannot find a childcare provider. To assure we hear a variety of perspectives, only one parent/guardian from each family may participate in the focus group.

We included a script for explaining the purpose of the focus group and recruiting participants, as well as an excel spreadsheet to track who agrees to participate. CHSC staff in Iowa City will use this list to contact families and remind them about the focus group.

Please try to send the **Confirmation Letter** and **Frequently Asked Questions** to families within 24 hours of an agreement to participate.

Helpful Tips for Regional Center Staff:

- Unless you are explicitly told to do so by someone in the household, please do not call before 9:30 am or after 9:00 pm.

- If the person who picks up the phone is not the parent or guardian and asks why you are calling, say that you are calling to talk about CHILD NAME. Do not reveal any more information to them.
- While we do not want to discourage willing participants from attending, we do want to discourage people who are unlikely to show up from agreeing to participate because they wish they could, because they are just trying to be nice, or for any other reason. If someone is unsure, let them know that we really need to be sure we have a good turnout – only commit if they are quite sure that they can come. Also please explain that if they cannot make it, to please contact NAME at NUMBER.
- Some people may wish to tell you their stories on the phone, but simply explain that the goal is to be able tell their stories as part of the group. If they cannot make it to the group, but want to share their thoughts, they may write them down and email it to you.

Frequently Asked Questions

How will a family's participation in this discussion affect the child or family receives?

A family's voluntary participation will **not** affect any services the child or family receives or can receive in the future.

Will the family's information will be kept confidential?

The full name of the child or parent/guardian will not be used during the discussion and will never be used in any report or document that is shared with others.

Why should families participate?

The information that families provide in these discussion groups will help improve programming and services for children and youth with special health care needs in Iowa.

How and when will families be paid?

Participants will be given \$60 right after the group discussion is completed.

Is child care available?

Child care is not available, however participants may allow their child to sit with them during the focus group if they cannot find a child care provider.

Is transportation available?

Sorry, we cannot provide transportation.

Can participants bring someone along (a friend or another parent)?

If another adult comes with the participant, they will be **not** be able to stay in the room where the discussion is held.

What will the group discussion be like?

- It will be 1 ½ hours long
- There will be 8 – 10 parents/caregivers and a group moderator
- Food and drinks will be provided
- The discussion will be private but, with the group's permission, will be tape recorded for use by the moderators only. The group moderator will begin by explaining the purpose of the group discussion and then ask questions about families' experiences and views about services for children and youth with special health care needs.

**Appendix H: Recruitment Script for Focus Groups with Families of Children and Youth With
Special Health Care Needs**

CITY FOCUS GROUP

DATE, TIME and LOCATION

Hello – my name is STAFF NAME. Every five years, Child Health Specialty Clinics talks with many families to determine how we can best meet their needs. We are working on this now, and would like to talk with your family during a two hour focus group discussion on DATE to discuss the services and systems of care you receive and need for CHILD NAME. If you are able to participate, we will give you \$60 to thank you for your time and effort.

FOR ENGLISH SPEAKING Families: Before we start can you tell me if English is your primary language? *[If yes, continue; if no, thank, say that we are looking for families who speak English to participate in a discussion, and end the call]*

As a thank you for participating, you will earn \$60. You will also help Child Health Specialty Clinics make sure children like yours receive the services and care they need.

1. Does this sound like something you might be interested in hearing a little more about and possibly participating?

- ☐ Yes *(If yes, continue to #2)*
- ☐ No *(If no, thank and close the discussion/call)*

2. Would it be OK if I ask you a few questions to see whether we are able to include you in the discussion?

- ☐ Yes *(If yes, continue to #3)*
- ☐ No *(If no, thank and close the discussion/call)*

3. Are you most comfortable communicating primarily in [English/Spanish]?¹

- ☐ Yes *(If yes, continue to #5)(NOTE: this criteria will be vetted earlier in the call)*
- ☐ No *(If no, thank and end the call)*

¹ NOTE: There are alternate ways to ask this question, including: Do you prefer to speak any language other than Spanish? Are you comfortable speaking in English?

The group discussion will take place on DATE, TIME, LOCATION.

4. Are you available to participate at that time?

- ☐ Yes *(If yes, continue to #6)--*
- ☐ No *(If no, thank and end the call)*

5. I will send you directions to the LOCATION after our call, but do you think you are you able to get to the LOCATION easily?

- ☐ Yes *(If yes, continue to #7)*
- ☐ No *(If no, thank and end the call)*

6. Will you be able to arrange for someone else to care for your child while you participate in the focus group?

- ☐ Yes *(Continue to #8)*
- ☐ No *(Explain that we are not able to provide child care onsite; They may bring the child to the group if necessary.*

7. If we can, we're hoping to have people from different places in this area; can you share the name of the town or city that you live in? _____

8. Great! I'd like to confirm that you are interested in participating in this group discussion on DATE to share your thoughts about the needs of your child and how the services and systems of care for your child can be improved. Are you interested in participating and do you think you will probably be able to at that date and time?

- ☐ Yes *(If yes, continue to #10)*
- ☐ No *(If no, thank and end the call)*

9. In order to send you a confirmation letter and email, and to call to remind you about meeting with us on DATE AND LOCATION, can you please provide me with your contact information? I would also like to ask for your address and an email address if you have one.

(Document this in the tracking form)

- Name (first and last)
- Telephone (second one too, if they have one)
- Email address

- Mailing address

Great – I'd like to go over a few things before we say goodbye and then see if you have any questions for me:

- If you are not able to make it to the focus group – you have a sick child, end up having to work, etc., please contact NAME AND PHONE NUMBER.
- The room may be a little crowded, so it is best if you come alone. But it is okay to bring your child with you if needed.
- We will provide \$60 for participating in the 2 hour group discussion
- I will send you a confirmation letter stating the date, time, and location for the discussion, as well as directions and key contact telephone numbers if you have more questions or are not able to make it.

Do you have any questions for me?

Great! Later today I will send you a confirmation letter with the details and directions to the group. In that letter you will see the name NAME. She is the best person to contact if you have any questions. But you can also contact me at XXX-XXX-XXX or address@xxx.com if you think of anything you want to ask before that. We are excited about your participation. Thank you.

**Appendix I: Confirmation Letter for Families of Children and Youth With Special Health Care
Needs Participating in Focus Groups**

DATE:

Dear Family,

As we discussed on the telephone, Iowa's Title V Program for children and youth with special health care needs is organizing a group discussion with parents and caregivers of children and youth with special health care needs. We want to hear what you think of the services you receive, your child's needs, challenges you may have in getting the care and services your child needs, and recommendations you have so we can improve the system of care for children and youth with special health care needs in Iowa.

For participating in the two-hour group discussion, you will receive \$60 to help compensate for your time and child care and travel costs. Food will also be provided.

The group discussion is scheduled to be held at:

(Insert location, date and time)

Only one parent or guardian from each family will be able to participate. If another adult comes with you they will **not** be able to join you in the room where the discussion is held.

We're glad that you are interested in participating. Your opinions are important to us and we hope you can make time to attend the discussion. All the information you provide will be completely private.

If you have any questions or if your plans change and you cannot attend the group, please contact NAME at Child Health Specialty Clinics at PHONE NUMBER so we can give another person a chance to participate.

Sincerely,

Insert staff member name and title

Appendix J: Informed Consent for Families of Children and Youth with Special Health Care Needs
Consent to Participate in Focus Group

You are being asked to participate in a group discussion to help better understand what works well and barriers or problems in Iowa's system of care serving children and youth with special health care needs and their families. Your participation is important to help improve the health care and related services that all children and youth with special needs in Iowa receive.

All of the information you provide will be kept confidential by the organizers of this meeting. Your name will never be included in any reports, and none of your answers will be linked to you in any way. Other participants in this group are *not required* to keep your information confidential. We ask that you respect the privacy of others and **do not repeat what is said in the focus group to others**.

You do not have to participate in this discussion group. Even if you agree to participate now, you may stop participating AT ANY TIME or refuse to answer ANY QUESTION. You will be paid \$60 even if you decide to stop participating in the focus group.

If you have any questions about this focus group, you may call NAME at PHONE NUMBER.
Thank you.

☐ I agree to take part in this group discussion and to be audio recorded. I have read the above group discussion description. Anything I did not understand was explained to me by the focus group facilitator and my questions were answered to my satisfaction.

Signature

Date

☐ I have received a \$60 from the group leader.

Signature

Date

**Appendix K: Informed Consent for Community-Based Providers of Children
and Youth with Special Health Care Needs**

Consent to Participate in Focus Group

You are being asked to participate in a group discussion to help better understand what works well and barriers or problems in Iowa's system of care serving children and youth with special health care needs and their families. Your participation is important to help improve the health care and related services that all children and youth with special needs in Iowa receive.

All of the information you provide will be kept confidential by the organizers of this meeting. Your name will never be included in any reports, and none of your answers will be linked to you in any way. Other participants in this group are *not required* to keep your information confidential. We ask that you respect the privacy of others and **do not repeat what is said in the focus group to others.**

You do not have to participate in this discussion group. Even if you agree to participate now, you may stop participating AT ANY TIME or refuse to answer ANY QUESTION. You will be paid \$40 even if you decide to stop participating in this focus group.

If you have any questions about this focus group, you may call NAME at PHONE

NUMBER. Thank you.

☐ I agree to take part in this group discussion and to be audio recorded. I have read the above group discussion description. Anything I did not understand was explained to me by the focus group facilitator and my questions were answered to my satisfaction.

Signature

Date

☐ I have received \$40 from the group leader.

Signature

Date

Appendix L: Discussion Guide for Focus Groups with Families of Children and Youth with Special Health Care Needs

B. WELCOME/BACKGROUND INFO

Welcome to our group discussion. Thank you for coming today and taking the time to participate in our focus group discussion about health care for children with special needs. My name is NAME I am here with my colleague NAME who works at the central office of the Child Health Specialty Clinics program in Iowa City and she will be listening carefully and taking notes and may offer some additional questions to you throughout our discussion. *[For groups with families of children with special health care needs: “As you know, your child is served by the Child Health Specialty Clinic in CITY. We are helping Child Health Specialty Clinics to learn more about the experiences of families like yours in getting the health care and supports needed when a child has a special health care need. We will use your ideas to provide recommendations that will help Child Health Specialty Clinics and other organizations working with them to improve the system of care for children and youth with special needs and their families in Iowa. Has everyone handed in the informed consent form and filled out the short anonymous survey?*

Have you received your thank you payment?

Okay we can begin. Have any of you ever been in a focus group before? The purpose of a focus group is to get the honest opinions of a small group of people about a specific topic. In order to be an effective way of obtaining information there are a few rules that it will be helpful to follow. I would like to review these ground rules now:

- There are no right or wrong answers. We are here to find out about your experiences and they may be very different.
- It is okay to disagree with one another. We want to hear everyone’s point of view. However if you disagree, please do so respectfully.
- I do not work directly for the Child Health Specialty Clinics or any other organizations in Iowa that provides services we will talk about today, so feel free to tell me your thoughts, whether they are positive or negative.
- Only one person should talk at a time. We are audio taping this session so that we do not miss anything important. If two people talk at once, we cannot understand what anyone is saying. I may remind you of this during the group.
- We would like everyone to participate. You do not have to answer every question. If, however, some of you are shy or I really want to know what you think about a particular topic, I may ask you about it.

- We have a lot to talk about today. So, do not be surprised if at some point I interrupt the discussion and move to another topic. But, if there is something important you want to say, let me know and you can quickly add your thoughts in before we change subjects.
- We will use first names only today. Everything you say is confidential. We will conduct several of these group discussions across the state, and then I will write a report for Child Health Specialty Clinics. Your name, or your child's name will not appear anywhere in the report. The tapes we make today will not be shared with any organizations, including Child Health Specialty Clinics staff. They will only get a written transcript that does not have any names in it. Anything you say today will not be attached to your name at any point. Nothing you say will affect your eligibility for the services you receive through any programs.
- Do not worry about offending us. We really want to learn from you and find out what you think about the issues we talk about today (*or tonight*). Please share your honest opinions.
- Lastly, I want to make a couple of points related to the audio recording. Please speak up. If you speak too quietly, it will be too difficult to hear you later on the tape to include your input. Also, please do not bump the table or tap your hands on the table. Anything close to the tape recorder sounds incredibly loud on the tapes and it will drown out your voices. NAME is also taking detailed notes in case the tapes do not come out clearly and she will be handling the tape recorder.

The group will last about an hour and a half. You will not get out any later than_____. We will not be taking a formal break, but if you need to leave for a restroom break, the bathrooms are _____.

Any questions at this point?

C. INTRODUCTIONS

Okay, let's get started.

Start with participant to your right. Have them respond in round robin fashion.

Please tell us your first name, how many children you have and their ages, and briefly describe your child's special health care needs.

D. ACCESS TO NEEDED SERVICES AND SUPPORTS

For the first part of our discussion today, I would like to ask you about the services you receive for your child, those you need but don't get, and what makes it easy or difficult to get the care you need for your child.

1. What medical services does your child receive? I am interested in not just what Child Health Specialty Clinics provides for your child, but all the types of medical care your child receives.

OPTIONAL PROBE (If not raised by discussants): What about mental health care services?

2. What other services and supports do you and your child receive related to his or her special needs?

OPTIONAL PROBES (If not raised by discussants): What about respite, home and school- based services, child care, family support groups)

3. Tell me about a time when you have had difficulty obtaining particular services that your child needs or needed.
4. What makes it possible or easier for you to get the medical and non-medical services your child needs?

OPTIONAL PROBE (If not raised by discussants): What services, if any do you receive over the phone or through webcam on your computer? How well does this work for you?

E. CARE COORDINATION

In this portion of our discussion, we are interested in learning about how the different kinds of services your child and family uses are coordinated, and how well different kinds of providers work together.

5. Raise your hand if you have a main place where you take your child for health care when your child is sick or needs a check-up or vaccination shots. [NOTE TO NOTETAKER-- DOCUMENT THE NUMBER OF RAISED HANDS AMONG THE GROUP e.g. "3 of 6 raised their hand"].

6. How well does this main place for care communicate about your child with other providers of health care services, such as speech therapists, occupational therapists, physical therapists or other medical specialists?

7. How well does this main place for care communicate with the school system about schoolwork or other services your child needs, such as early intervention services or special accommodations in their school setting?

8. How do they share this information about their communication with other health care providers and the school system with you?

E. MEDICAL HOME/HEALTH HOME

Now, I would like to talk about the “Health Home” model of care, that is starting up in Iowa for some groups of CYSCHN (sometimes also referred to as a “Medical Home”).

(READ DEFINITION OF A HEALTH HOME BELOW)

A Health Home is not a place. It is an approach to care where your family receives support and assistance with coordinating health care and other services. The health home should provide services in a culturally sensitive way. With a health home approach, you should always feel like a partner in your child’s care. A Health Home approach provides care coordination to make sure your child’s doctors and other agencies who work with your child or family have up to date information.

What do you think of this concept of care of a health home for children?

10. Please tell me where along the continuum shown in this diagram do you feel that your child’s health care falls and why you think it falls there?

11. Raise your hand if you have an office or agency with staff who help you get connected to medical services and non-medical community resources for your child and family. Sometimes this kind of help is called Care Coordination (Examples: this can include specialists, different kinds of therapy and respite providers, education agencies, or community resources that can help with things like housing assistance or parenting support)[NOTE TO NOTETAKER-- DOCUMENT THE NUMBER OF RAISED HANDS AMONG THE GROUP e.g. “3 of 6 raised their hand”].

PROBE: For those of you who did not raise your hands, how do you find out about other medical services your child might need? How do you find out about other non-medical community resources to help your child and family?

F. FAMILY/PROFESSIONAL PARTNERSHIPS

We are interested in learning how the providers in the health care system for your child communicate with you and how involved you feel in making decisions about your child’s care. So I will ask you a few questions to help us understand this better.

12. First, with a show of hands how many of you feel that the overall health care system includes you as a partner in making decisions about the care of your child?

PROBES:

- a) If you answered yes, how are you included you as a partner in these decisions?
- b) If you answered no, what makes you feel that you are not included as a partner in making these decisions?

13. How does the health care system for your child support your well-being and address your needs?

G. CULTURAL/LANGUAGE BARRIERS

We are also interested in knowing more about how well you and your child's doctors or other health care providers understand each other. I am talking about things like your lifestyle, your language, your beliefs, your background, and your health care decisions. So I will ask you some questions to help us understand that a bit more.

14. How has your family's religious or spiritual beliefs affected the health care that your child receives? Was there anything that providers should have done differently to show more respect to these beliefs?

15. In what ways did your cultural or ethnic background affect the health care that your child has received?

16. Do your child's providers use words that are easy for you to understand when speaking with you?
Follow-up: How clearly do your providers explain your child's condition and what you need to do when you get home?

H. TRANSITION

17. For those of you with children with special health care needs over the age of 12, have your child's health care providers ever spoken with you and your child about ways to make your child's transition to the adult health system easier?

18. Have your child's health care providers spoken to you about transition to college or work?

19. What information do you feel would be helpful to make these transitions easier for your child and your family?

I. ADDITIONAL RECOMMENDATIONS FOR IMPROVEMENT

In addition to what you have already discussed I would like to offer you the opportunity to make recommendations to help make sure children and families like yours get the services they need

20. What advice or suggestions do you have to improve access to quality care and services for children and youth with special health care needs in your community and your state? (food insecurity, transportation, language, hours, etc.)

(PROBE BASED ON PREVIOUS DISCUSSION)

J. CLOSING AND THANK YOU

Is there anything else we did not discuss today that seems relevant?

Thank you so much for coming today. Your time is very much appreciated and your comments have been VERY helpful. After today we are going to take the written notes and transcribe the tape recording. Your input will be combined with what we heard from families in focus groups in other communities around the state into a report for Child Health Specialty Clinics. They will use these findings to improve how they reach out to families like yours. They will also use this information to strengthen partnerships with families, service providers, state agencies, policymakers across Iowa to improve the system of care for children and youth with special health care needs.

Before you leave, please make sure you have received your thank you payment and have signed the acknowledgment form. Thank you again for taking out time from your busy lives to come here and contribute today.

**Appendix M: Discussion Guide for Focus Group of Community-Based Providers for
Children and Youth With Special Health Care Needs**

A. WELCOME/BACKGROUND INFO

Welcome to our group discussion. Thank you for coming today and taking the time to participate in our focus group discussion about health care for children and youth with special needs. My name is NAME, I am here with my colleague NAME who will be listening carefully and taking notes and may offer some additional questions to you throughout our discussion. We are helping Iowa's Title V program for Children and Youth with Special Health Care Needs learn more about the experiences of providers like you and the families you serve. We will use your ideas to provide recommendations that will help the Title V program for Children and Youth with Special Health Care Needs, Iowa Department of Public Health, Child Health Specialty Clinics, and other organizations working with them to improve the system of care for children and youth with special needs and their families in Iowa. Has everyone handed in the informed consent form and filled out the short anonymous survey?

Okay we can begin. Have any of you ever been in a focus group before? The purpose of a focus group is to get the honest opinions of small groups of people about a specific topic. In order to be an effective way of obtaining information there are a few rules that it will be helpful to follow. I would like to review these ground rules now:

- There are no right or wrong answers. We are here to find out about your experiences and they may be very different.
- It is okay to disagree with one another. We want to hear everyone's point of view. However if you disagree, please do so respectfully.
- I do not work directly for IDPH, Child Health Specialty Clinics or any other organizations in Iowa that provides services we will talk about today, so feel free to tell me your thoughts, whether they are positive or negative.
- Only one person should talk at a time. We are audio taping this session so that we do not miss anything important. If two people talk at once, we cannot understand what anyone is saying. I may remind you of this during the group.
- We would like everyone to participate. You do not have to answer every question. If, however, some of you are shy or I really want to know what you think about a particular topic, I may ask you about it.
- We have a lot to talk about today. So, do not be surprised if at some point I interrupt the discussion and move to another topic. But, if there is something important you want to say, let me know and you can quickly add your thoughts in before we change subjects.
- We will use first names only today. Everything you say is confidential. We will conduct several of these group discussions across the state, and then I will write a report for Child Health Specialty Clinics. Your name, or your child's name will not appear anywhere in the report. The tapes we make today will not be shared with any organizations. They will get a written transcript that does not have any names in it. Anything you say today will not be attached to your name at any point.

- Do not worry about offending us. We really want to learn from you and find out what you think about the issues we talk about today (*or tonight*). Please share your honest opinions.
- Lastly, I want to make a couple of points related to the audio recording. Please speak up. If you speak too quietly, it will be too difficult to hear you later on the tape to include your input. Also, please do not bump the table or tap your hands on the table. Anything close to the tape recorder sounds very loud on the tapes and it will drown out your voices. NAME is also taking detailed notes in case the tapes do not come out clearly and she will be handling the tape recorder.

The group will last about an hour and a half. You will not get out any later than _____. We will not be taking a formal break, but if you need to leave for a restroom break, the bathrooms are _____.

Do you have any questions at this point?

B. INTRODUCTIONS

Okay, let's get started.

Start with the participant to your right. Have them respond in round robin fashion.

Please tell us your first name, what kind of health care provider you are, and a little bit (no more than one minute please) about the kinds of children with special health care needs that you and your practice serve.

C. ABILITY TO ADEQUATELY SERVE CYSHCN

In this first section of our discussion we would like to hear what makes it easy or hard for you to provide adequate care for children and youth with special health care needs.

1. Let's start with what helps you to be able to serve children and youth with special health care needs. Tell us about the factors that facilitate your ability to adequately care for children and youth with special health care needs?
2. Now, tell us what the factors make it hard or challenge your ability to adequately care for children and youth with special health care needs?
3. What would make it easier for you to more adequately serve children and youth with special health care needs?

D. CARE COORDINATION

As you know, children and youth with special health care needs and their families require a wide range of medical, psychosocial, educational, and support services. As you have just described, assisting families of children with special health care needs can sometimes be challenging. Additionally, assuring

that their care is coordinated across the many different providers and agencies that they need services from can be a challenging goal.

4. If you or your workplace provides care coordination for families of children with special health care needs, please tell us how you do this?
5. If you do not provide care coordination for these families, please describe whether and how you think care is coordinated for these families?
6. How do you think care coordination should be provided for these families?

E. MEDICAL HOME/HEALTH HOME

Now, I would like to talk about the “Health Home” model of care for children (sometimes also referred to as the “Medical Home”) that is starting up in Iowa for some groups of CYSHCN.

A Health Home is not a place. It is an approach to care where your family receives support and assistance with coordinating health care and other services. The health home should provide services in a culturally sensitive way. With a health home approach, parents/caregivers should always feel like a partner in their child’s care. A Health Home approach provides care coordination to make sure the child’s doctors and other agencies who work with the family have up to date information. (refer to Health Home graphic)

7. What do you think of this concept of care of a “health home” for children?
8. By whom and how do you think a “health home” should be provided for children and youth with special health care need?

F. PARTNERING WITH OTHER COMMUNITY PROVIDERS

In this next section I would like to ask you about how you partner with community providers and families and what you need to help you more successfully partner with them.

9. First, please briefly tell us what community providers, if any, you currently work with or partner with in serving children with special health care needs and their families? By community providers I mean, for example, therapists, staff at non-profit organizations, social workers at Department of Human Services.
10. What do you need to help you more successfully partner with other community providers?

G. FAMILY/PROFESSIONAL PARTNERSHIPS

Now let's turn to the topic of partnering with families.

11. Please tell us about any ways that you usually involve families of children with special health care needs in the care planning process for their children?
12. Are families of children with special health care needs involved in any other ways in your organization, for example in an advisory role or as Family Navigators?
13. What do you need to help you more successfully partner with families of children with special health care needs?

H. FACTORS AFFECTING ACCESS TO CARE

14. What do you think are key barriers to accessing needed services for families of children with special health care needs in your area?
15. Again, speaking from your experience in this area of Iowa, what access barriers do particular types of families with special needs children face, such as: families from different cultural, racial or ethnic groups, families with younger or older parents, foster families, parents who speak no or limited English, or any other groups you think have special barriers to accessing needed care ?

I. TRANSITIONING YOUTH TO ADULthood

How many of you serve youth ages 12 and older who have special health care needs?

16. What are your greatest challenges in transitioning youth you see to adult providers and an adult model of care?
17. Do you have enough information to help families with key transitions across the lifespan, including at the transition to school age, to middle school, to high school, and to adulthood)

J. FINANCING OF CARE FOR CYSCHN

Now I would like to switch the focus of our conversation to talk about the financing of care for CYSHCN. There are many changes going on in Iowa and nationwide on the financing and management of health care systems to improve access, value and health outcomes.

18. What do you see as the opportunities and challenges related to financing services needed for children and youth with special health care needs in Iowa?

K. RECOMMENDATIONS FOR IMPROVEMENT

In this last section of our discussion, I would like to offer you the opportunity to make recommendations for how to help make sure children and youth with special health care needs and their families have access to a quality, comprehensive system of services and support to promote their healthy development, maximum potential, and overall wellbeing.

19. What advice or suggestions do you have for Child Health Specialty Clinics specifically?
20. What other recommendations do you have for how care and services for children and youth with special health care needs can be improved in your community and your state?

L. CLOSING AND THANK YOU

Thank you so much for your time and thoughtful input today. It has been a pleasure meeting you and hearing your experiences and excellent ideas.

After today we are going to take the written notes and transcribe the tape recording. Child Health Specialty Clinics will use these findings both to improve how they reach out to and work with individual providers like yourselves, as well as to help them prioritize the kinds of training and supports they offer providers around the state. It will also provide feedback on how Child Health Specialty Clinics should be involved in quality assurance, financing of health care and educating policy makers. Addressing these topics collectively will improve the system of care for children and youth with special health care needs across Iowa and improve the lives of these children and their families.

Before you leave, please make sure you have received your thank you payment and have signed the acknowledgment form. Thank you again for taking time out from your busy lives to provide input to enhance Iowa's system of care for children and youth with special health care needs.

**Appendix N: Demographic Survey for Focus Groups with Families of
Children and Youth with Special Health Care Needs**

Please **do not** write your name or your child's name on this paper. If you do not wish to provide an answer to a question, please leave it blank.

1. What is your relationship to your child?
Mother/Step-mother
Father/Step-father
Grandparent
Other: please describe _____
2. Please write in the age of each of your children with special health care needs.
Child one: _____ Child two: _____ Child three: _____ Child four: _____
3. What kind of health insurance do your children have?
No health insurance
Medicaid
hawk-i
Military
Indian Health Service
Private insurance (please list) _____
Other (please describe) _____
4. Is your child with a special health care need of Hispanic or Latino origin? Yes
No
5. Please choose one or more category to describe the race of your child.
White
Black or African American
American Indian or Alaskan Native
Asian
Native Hawaiian or other Pacific Islander
Other
6. What is the primary language spoken in your home?
English
Spanish
7. What is the primary diagnosis of your child (or children) who has a special health care need?

8. Do you consider your child's condition to be minor, moderate, or severe? (Circle below)
Minor Moderate Severe

THANK YOU!

**Appendix O: Demographic Survey for Focus Group of Community-Based Providers of Children
and Youth with Special Health Care Needs**

Some Information about You

*Please **do not write your name** on this paper. If you do not wish to provide an answer to a question, leave it blank.*

1. What type of provider are you?

Pediatrician

Family Practitioner

Medical Specialist (specialty: _____)

Child Care

Social Worker

Behavioral Health

Mental Health

Respite

Family Support

Therapist (Speech, OT, PT)

Other: please describe _____

2. How often do you interface with Iowa's Title V Program for Children and Youth with Special Health Care Needs?

____ Never

____ Rarely

____ Sometimes

____ Often

3. How long have you been working in your field?

Less than one year

1-3 years

4-6 years

7-10 years

10+ years

4. How long have you been working in Iowa?

Less than one year

1-3 years

4-6 years

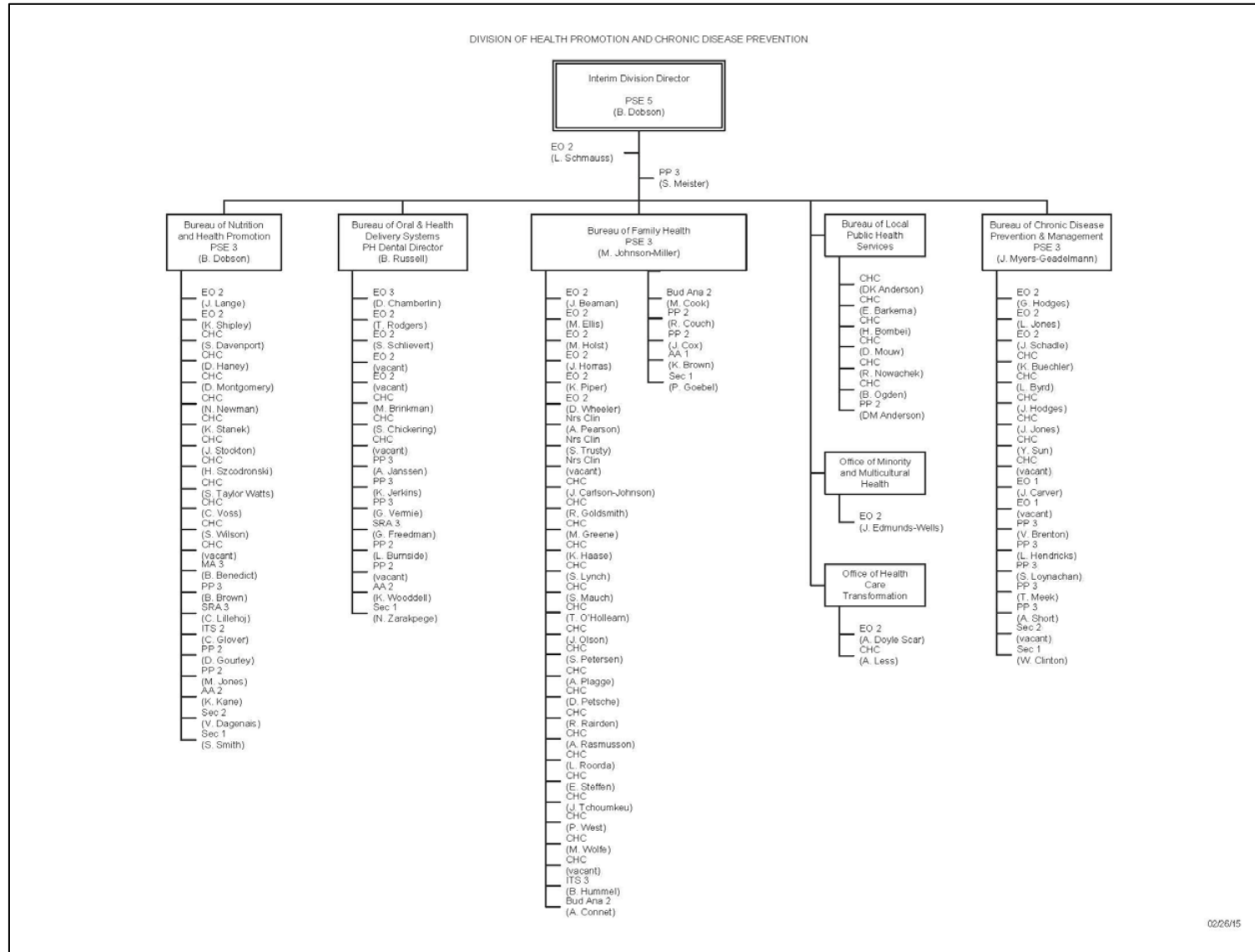
7-10 years

10+ years

5. Would you describe yourself as being Hispanic or Latino?
- Yes
- No
6. Please choose one or more category to describe your race.
- White
- Black or African American
- American Indian or Alaskan Native
- Asian
- Native Hawaiian or other Pacific Islander
- Other

THANK YOU!

Appendix P: Tables of Organization



Bureau of Family Health
Bureau Chief/PSE3
Marcus Johnson-Miller

BFH Infrastructure and Performance Management

- Andrew Connet – fiscal/contracts
- Misty Cook – fiscal/contracts
- Kim Brown – support staff
- Patrick Goebel – support staff
- Brad Hummel – CARES TA

Early Childhood and CCID

Kim Piper

- Rhonda Rairden- Project LAUNCH
- Tammy O’Hollearn- EHDI Coordinator
- Esha Steffen- EHDI Short Term Follow Up Coordinator (Field Office)
- Shalome Lynch – EHDI Follow-Up (.75 FTE)
- Jini Cox- EHDI
- Meghan Wolfe- Early ACCESS
- Michelle Holst – 1st Five
- Rebecca Goldsmith- 1st Five
- James Olson- ECCS and ECI

Reproductive/ Maternal/ Women’s Health

Denise Wheeler

- Stephanie Trusty- MH/FP
- Di Petsche- MH/FP
- Sarah Mauch- PRAMS
- Debbie Kane – MCH Epi
- Addie Rasmusson- PREP and Adolescent Health
- Mary Greene- Ab Education and Adolescent Health
- Jennifer Pham- PRAMS temp
- Greg Freedman – PT PRAMS
- Brittnei Frederickson - CDC/CSTE Applied Epidemiology Fellow

Home Visiting

Janet Horras

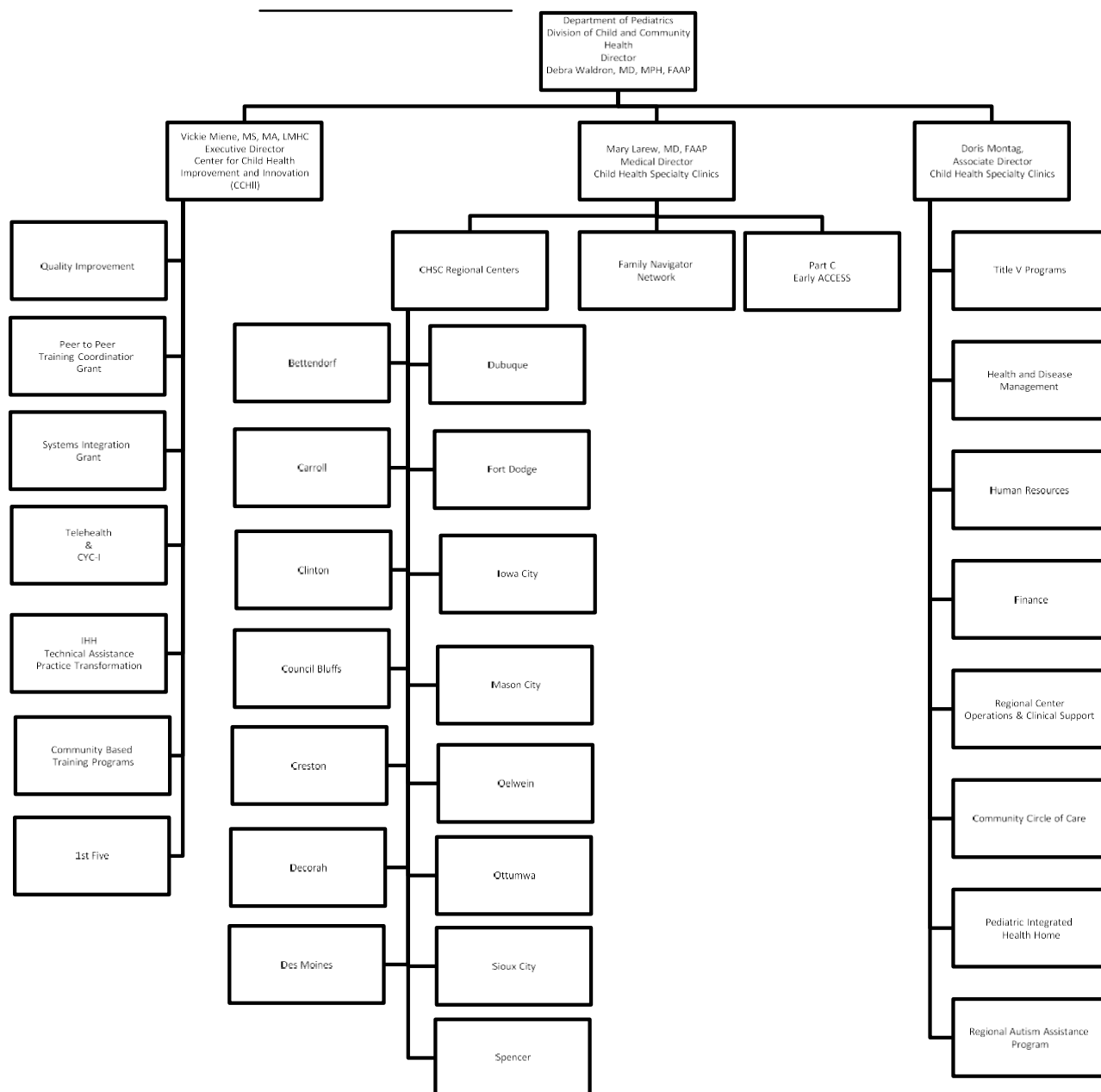
- PJ West- MIECHV and HOPES
- Jean Johnson- MIECHV PD
- Lance Roorda-MIECHV Service Coordinator
- Julie Tchoumkeu- MIECHV QA
- Anne Plagge- MIECHV Tech/BFH Graphic design
- Temporary Employees:
 - Kelly Schulte
 - Caitlin Suginaka

Child and Adolescent Health

Janet Beaman

- Roger Couch – QA team
- Kelly Haase- QA Team
- VACANT- Data Integration
- Analisa Pearson- EPSDT
- Sylvia Petersen -hawk-i Outreach Coordinator
- Melissa Ellis – Discretionary grants
- Heidi Hotvedt- HCCI temp

University of Iowa Division of Child and Community Health-Organizational Chart (4/10/15)



Appendix Q: IDPH Maternal and Child Health Contracts and Memoranda of Agreement

<u>Service Type</u>	<u>Agency/Location</u>	<u>Name of Contract(s)</u>
Child Health – Dental		
	Black Hawk County, Waterloo	Sealant Project
	Hawkeye Area Community Action Program, Inc. Hiawatha	Sealant Project Lee
	County Health Department, Ft. Madison	Sealant Project
	Mid-Iowa Community Action, Marshalltown	Sealant Project
	Mid-Sioux Opportunity, Sioux City	Sealant Project
	Trinity Muscatine Public Health, Muscatine	Sealant Project
Outreach	Iowa State University Extension, Ames	MCH 1-800 Healthy Families Line
Staff Development/Education		
	University of Iowa, Iowa City	Professional Development
Community-based MCH Services		
	Allen Women's Health, Waterloo	Maternal Health
	American Home Finding, Ottumwa	Maternal & Child Health
	Black Hawk County Health Department, Waterloo	Child Health, 1 st Five
	Marion County Public Health, Knoxville	Maternal & Child Health
	New Opportunities, Carroll	Maternal & Child Health
	Crawford County Public Health, Denison	Maternal & Child Health
	Visiting Nurse Association, Dubuque	Child Health, 1 st Five
	FAMILY, Inc., Council Bluffs	Maternal & Child Health
	HACAP, Cedar Rapids	Maternal & Child Health
	Hillcrest Family Services, Dubuque	Maternal Health Johnson
	County Health Department, Iowa City	Maternal & Child Health
	Lee County Health Department, Ft Madison	Maternal & Child Health, 1 st Five
	MATURA Action Corporation, Creston	Maternal & Child Health
	Mid-Iowa Community Action, Marshalltown	Maternal & Child Health, 1 st Five
	Mid-Sioux Opportunity, Remsen	Maternal & Child Health
	North Iowa Community Action Organization, Mason City	Maternal & Child Health
	Scott County Health Department, Davenport	Child Health
	Siouxland District Health Department, Sioux City	Maternal Health (and Child Health as of 5/1/14)
	Taylor County Health Department, Bedford	Maternal & Child Health, 1 st Five
	Trinity Muscatine Public Health, Muscatine	Maternal & Child Health Visiting
	Nurse Services, Des Moines	Maternal & Child Health, 1 st Five
	Warren County Health Services, Indianola	Maternal & Child Health, 1 st Five
	Washington County, Washington	Maternal & Child Health Webster
	County Health Department, Fort Dodge	Maternal & Child Health
Personal Responsibility Education Program		
	Allen Memorial Hospital	PREP
	Bethany Children & Families	PREP
	Cerro Gordo County Health Department	PREP
	Community Youth Concepts	PREP
	Planned Parenthood of the Heartland	PREP
	Women's Health Services	PREP
Abstinence Education Grant Program		
	Youth and Shelter Services	AEGP
	Planned Parenthood	AEGP
	Oklahoma Institute for Child Advocacy	AEGP
	Community Youth Concepts	AEGP
<u>Service Type</u>	<u>Agency/Location</u>	<u>Name of Contract</u>

Maternal, Infant, Early Childhood Home Visitation Program

Lee County Health Department Lutheran Services of Iowa IFSTAN	MIECHV Expansion of MIECHV, Iowa Family Support Credentialing
Mid-Iowa Community Action Operation Threshold Promise Partners Siouxland Human Investment Southern Iowa Economic Development Association Upper Des Moines Opportunity	Expansion of MIECHV MIECHV Expansion of MIECHV Expansion of MIECHV MIECHV Expansion of MIECHV

Infrastructure Building

University of Iowa, Iowa City University of Iowa, Iowa City University of Iowa, Iowa City University of Iowa, Iowa City University of Iowa, Iowa City University of Iowa, Iowa City University of Iowa, Iowa City University of Iowa, Iowa City University of Iowa, Iowa City University of Iowa, Iowa City	Hygienic Lab Birth Defects & Genetic Cons. Muscular Dystrophy Mobile Regional CHSC Statewide Perinatal Care Stillbirth Surveillance SSDI MCH Consultant Hearing Screening Vision Screening Child & Family Health Needs Assessment Household Health Survey Barriers to Prenatal Care Infant Mortality Prevention
University of Iowa, Iowa City University of Northern Iowa, Cedar Falls Iowa SIDS Foundation	

State Interagency Memoranda

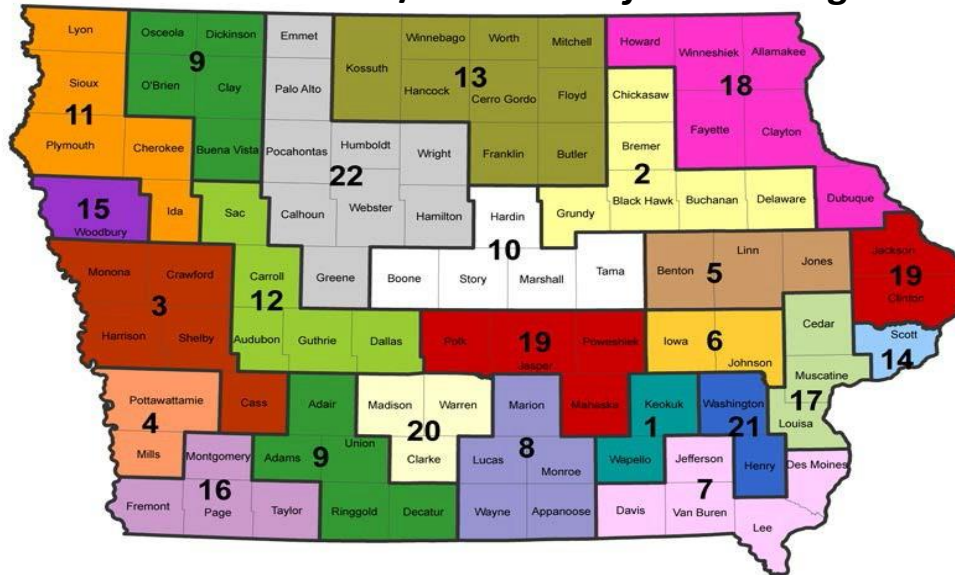
Iowa Department of Education Iowa Department of Human Services	Early ACCESS (IDEA, Part C) Cooperative Agreement Outreach Activities EPSDT Program Healthy Child Care Iowa Medicaid Administrative Services
Iowa Department of Management	Early Childhood Iowa Professional Development

CONTRACTS AND MEMORANDA OF AGREEMENT IOWA CHILD HEALTH SPECIALTY CLINICS

<u>Agency</u>	<u>Name of Contract</u>
Iowa Chapter of the American Academy of Pediatrics	Help Me Grow National Replication Project Executive Director Contract
Iowa Department of Education	Regional Autism Assistance Program Early ACCESS (IDEA, Part C)
Iowa Department of Public Health	Cooperative Programmatic Agreement 1 st Five Child Metric and Primary Care Provider Consultation Iowa Autism Fund
Iowa Department of Human Services	Early and Periodic Screening, Diagnosis and Treatment Health and Disease Management Program University of Iowa CHSC Community Circle of Care IDEA – Part C (Early ACCESS) Interagency MOA 2013-2018
Iowa Department of Human Services, Iowa Department of Education and Iowa Department of Public Health Magellan Health Services and University of Iowa Hospitals and Clinics, Department of Pediatrics	Center for Child Health Improvement and Innovation

Appendix R: Title V Program Service Maps

Title V Child Health/EPSTD *Care for Kids* Program



1. American Home Finding Association
333 Church Street
Ottumwa, IA 52501
Denise Janssen (641) 682-8784 (800) 452-1098

2. Black Hawk County Health Department
1407 Independence Avenue, 4th Floor
Waterloo, IA 50703
Arlene Prather-O'Kane (319) 291-2413

3. Crawford County Home Health, Hospice, & PH
105 North Main Street
Denison, IA 51442
Deb Birks (712) 263-3303

4. FAMILY, Inc.
3501 Harry Langdon Blvd. Suite 150
Council Bluffs, IA 51503
Lee Baratta (712) 256-9566

5. Hawkeye Area Community Action Program, Inc.
1515 Hawkeye Drive
Hiawatha, IA 52233
Gloria Witzberger (319) 739-1531 (800) 332-5289

6. Johnson County Public Health
855 South Dubuque Street, Suite 217
Iowa City, IA 52240
Erica Wagner (319) 688-5891

7. Lee County Health Department
2218 Avenue H
Ft. Madison, IA 52627
Melissa Calvillo (319) 372-5225 (800) 458-6672

8. Marion County Public Health
2003 North Lincoln P.O. Box 152
Knoxville, IA 50138
Rachel Cecil (641) 828-2238 Ext. 241

9. MATURA Action Corporation
207 B North Elm Street
Creston, IA 50801
Karla Hynes (641) 202-7114

10. Mid-Iowa Community Action, Inc.
1001 South 18th Avenue
Marshalltown, IA 50158
Nicole Dudley (641) 752-7162

11. Mid-Sioux Opportunity, Inc.
418 South Marion Street
Remsen, IA 51050
Karina Nonnemacher (712) 786-3418 (800) 859-2025

12. New Opportunities, Inc.
23751 Hwy 30, P.O. Box 427
Carroll, IA 51401
Beth Liechti (712) 792-9266 Ext. 217 (800) 642-6330

13. North Iowa Community Action Organization
100 1st Street NW; Suite 200
Mason City, IA 50401
Lisa Koppin (641) 423-5044 Ext. 17 (800) 657-5856

14. Scott County Health Department
600 West 4th Street, 4th Floor
Davenport, IA 52801
Tiffany Tjepkes (563) 326-8618 Ext. 8816

15. Siouxland District Health Department
1014 Nebraska Street
Sioux City, IA 51105
Sharon Schroeder (712) 224-5424

16. Taylor County Public Health
405 Jefferson Street
Bedford, IA 50833
Julie Thomas (712) 523-3405 (800) 425-0051

17. Trinity Muscatine Public Health
1609 Cedar Street
Muscatine, IA 52761
Rebecca Schultz (563) 263-0122

18. Visiting Nurse Association of Dubuque
1454 Iowa Street, P.O. Box 359 Dubuque, IA 52004
Stacey Killian (563) 556-6200 (800) 862-6133

19. Visiting Nurse Services of Iowa
1111 9th Street, Suite 320
Des Moines, IA 50314
Terri Walker (515) 558-9955

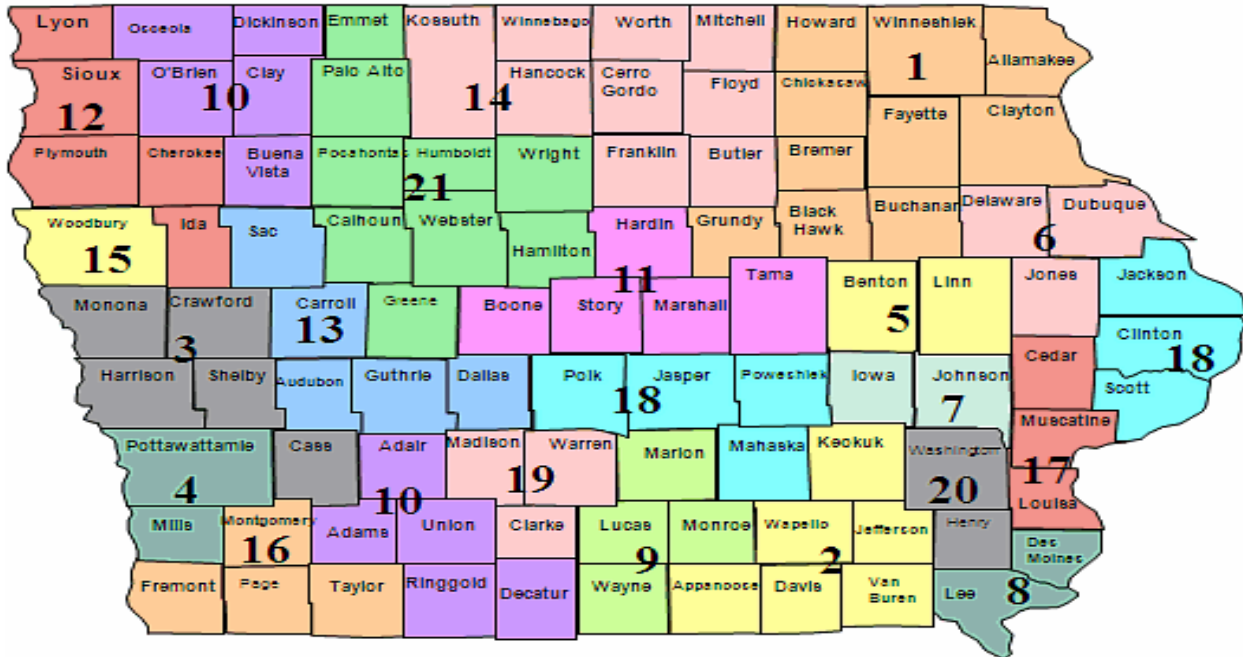
20. Warren County Health Services
301 North Buxton; Suite 203
Indianola, IA 50125
Angela Carlson (515) 961-1074

21. Washington County Public Health & Home Care
110 North Iowa Avenue, Suite 300
Washington, IA 52353
Jen Weidman (319) 653-7758 Ext. 104 (800) 655-7758

22. Webster County Health Department
723 1st Avenue South
Fort Dodge, IA 50501
Tricia Nichols (515) 573-4107 (888) 289-3318

July 2014

Location of Maternal Health Services



Project Period: FFY 2011 – 2015 Funding Source: Title V Block Grant and Medicaid Fee for Service Contact :Stephanie Trusty

Location of Maternal Health Services FFY 2015

1. **Allen Memorial Hospital**
Women's Health Center
233 Vold Drive
Waterloo, IA 50703
(319) 235-5090
2. **American Home Finding Association**
333 Church Street
Ottumwa, IA 52501
(641) 682-8784 (800) 452-1098
3. **Crawford County Home Health, Hospice, & PH**
105 North Main Street
Denison, IA 51442
(712) 263-3303
4. **Family Inc.**
3501 Harry Langdon Blvd. Suite 150
Council Bluffs, IA 51503
(712) 256-9566
5. **Hawkeye Area Community Action Program, Inc.**
1515 Hawkeye Drive
Hiawatha, IA 52233
(319) 393-7811
6. **Hillcrest Family Services**
220 W. 7th Street
Dubuque, IA 52001
(563) 589-8595
7. **Johnson County Public Health**
855 South Dubuque Street, Suite 217
Iowa City, IA 52240
(319) 356-6040
8. **Lee County Health Department**
2218 Avenue H
Ft. Madison, IA 52627
(319) 372-5225 (800) 458-6672
9. **Marion County Public Health**
2003 North Lincoln; P.O. Box 152
Knoxville, IA 50138
(641) 828-2238
10. **MATURA Action Corporation**
203 West Adams Street
Creston, IA 50801
(641) 782-8431
11. **Mid-Iowa Community Action, Inc.**
1001 South 18th Avenue
Marshalltown, IA 50158
(641) 752-7162
12. **Mid-Sioux Opportunity, Inc.**
418 South Marion Street
Remsen, IA 51050
(712) 786-2001 (800) 859-2025
13. **New Opportunities, Inc.**
23751 Hwy 30, P.O. Box 427
Carroll, IA 51401
(712) 792-9266 (800) 642-6330
14. **North Iowa Community Action Organization**
100 1st Street NW; Suite 200
Mason City, IA 50401
(641) 423-5044 (800) 657-5856
15. **Siouxland District Health Department**
1014 Nebraska Street
Sioux City, IA 51105
(712) 279-6119 (800) 587-3005
16. **Taylor County Public Health**
405 Jefferson Street
Bedford, IA 50833
(712) 523-3405 (800) 425-0051
17. **Trinity Muscatine Public Health**
1609 Cedar Street
Muscatine, IA 52761
(563) 263-0122
18. **Visiting Nurse Services of Iowa**
1111 9th Street, Suite 320
Des Moines, IA 50314
(515) 288-1516
19. **Warren County Health Services**
301 North Buxton; Suite 203
Indianola, IA 50125
(515) 961-1074
20. **Washington Co Public Health & Home Care**
110 North Iowa Avenue, Suite 300
Washington, IA 52353
(319) 653-7758 (800) 655-7758
21. **Webster County Health Department**
330 1st Avenue North, Suite L-2
Fort Dodge, IA 50501
(515) 573-4107 (888) 289-3318

October 2014

Map of UI Division of Child and Community Health Regional Centers

